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**IN THE  
SUPREME COURT OF THE UNITED STATES**

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October Term, 1998

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**TOMMY OLMSTEAD, Commissioner of the Department of  
Human Resources of the State of Georgia, et al.,  
Petitioners,**

**v.**

**L.C. and E.W., each by JONATHAN ZIMRING, as guardian ad  
litem and next friend,  
Respondents.**

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**ON WRIT OF CERTIORARI TO THE UNITED  
STATES COURT OF APPEALS FOR THE  
ELEVENTH CIRCUIT**

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**AMICI CURIAE BRIEF OF  
ADAPT, NATIONAL COUNCIL ON INDEPENDENT  
LIVING, AND TASH IN SUPPORT OF RESPONDENTS**

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## AMICI CURIAE BRIEF IN SUPPORT OF RESPONDENTS

### INTERESTS OF AMICI CURIAE

Amici are three national organizations composed primarily of persons with severe physical disabilities, including persons with spina bifida, cerebral palsy, muscular dystrophy, spinal cord injuries, multiple sclerosis, quadriplegia, paraplegia, head and brain injuries, poliomyelitis, amyotrophic lateral sclerosis, persons with sensory disabilities, and persons with cognitive, mental and developmental disabilities.<sup>1</sup>

Many of these persons have been unnecessarily segregated in nursing homes and other institutional facilities solely because they have disabilities, and many testified before Congress in support of ending unnecessary segregation.<sup>2</sup>

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<sup>1</sup> All parties have consented in writing to filing of this brief. Copies of the written consents are on file with the Clerk of the Supreme Court. Pursuant to 37.6 of the Supreme Court rules, none of the parties authored this brief in whole or in part and no one other than the amici or counsel contributed money or services to the preparation and submission of this brief.

<sup>2</sup> See *infra*, nn 32-38. Because other amici will discuss discrimination faced by people with developmental disabilities and mental disabilities, the present amici will focus on persons who have severe physical disabilities who are unnecessarily segregated in institutional facilities.

ADAPT, National Council on Independent Living ("NCIL") and TASH have a long history and record of enforcing the civil rights of people with disabilities, including the integration of disabled people into all aspects of society. They were key organizations that participated in the political and legislative process to pass the 1990 Americans With Disabilities Act, 42 U.S.C. § 12101 et seq., the civil rights statute for disabled persons, as well as the Fair Housing Act Amendments of 1988, 42 U.S.C. § 3604 et seq., and amendments to Individuals with Disabilities Education Act, 20 U.S.C. § 1400 et seq.<sup>3</sup>

### Summary of Argument

The Court's decision in the present case will have significant ramifications for people with severe physical disabilities who are unnecessarily in nursing facilities and other institutions. As Attorney General Janet Reno stated in May, 1998,

[w]e believe that states have an obligation to provide services to people with disabilities in the most integrated setting appropriate to their needs.... Many individuals with disabilities are being placed in

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<sup>3</sup> They have been plaintiffs in numerous cases including, inter alia, ADAPT v. Skinner, U.S. Department of Transportation, 867 F.2d 1471, 881 F.2d 1184 (3d Cir. 1989), filed an amicus curiae brief in Vacco, et al. v. Quill, et al., 117 S.Ct. 2293 (1997), and two currently are plaintiffs in ADAPT, et al. v. HUD, No. 98-1308 (3<sup>rd</sup> Cir. 1998)(pending).

nursing homes or other institutional settings even when they don't really need to be there.<sup>4</sup>

Throughout the country, community-based programs exist and could be used to prevent such unnecessary segregation. In addition to ending such segregation, these community-based programs often cost significantly less than the cost in the institutions. Helen L. v. DiDario, 46 F.3d 325, 332- 33 and 335 (3rd Cir. 1995), cert. denied, 116 S. Ct. 24 (1995), sub nom. Secretary of DPW of Pa. v. Idell S. ("ADA and its attendant regulations clearly define unnecessary segregation as a form of illegitimate discrimination against the disabled... [and that the] ADA is intended to insure that qualified individual receives services in a manner consistent with basic human dignity rather than a manner which shunts them aside, hides and ignores them").

Congress enacted the ADA not in a vacuum but with the benefit of years' worth of experience with the Rehabilitation Act of 1973, 29 U.S.C. § 794. In 1983, ten years after the Rehabilitation Act had been enacted, the United States Commission on Civil Rights noted "the ill effects of segregation," pointing out that:

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<sup>4</sup> Reprinted in National Conference of State Legislatures, Personal Assistance Services for People with Disabilities, 24 State Legislative Report at 1 (Jan. 1999)(emphasis added).



'Institutions serve two central purposes. First, they segregate disabled people from the community; and second they provide convenience for administrators....

'As vehicles of administrative convenience, they are ... successful....'

Institutionalization almost by definition entails segregation and isolation.... Indeed, a desire to segregate handicapped people from the rest of society prompted the development of residential institutions.<sup>5</sup>

Congress intended to "provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." 42 U.S.C. § 12101(b)(1)(emphasis added). Following the Commission on Civil Rights, Congress explicitly found that "historically, society has tended to isolate and segregate" disabled persons. 42 U.S.C. § 12101(a)(2)(emphases added). One of Congress' explicit Findings was that discrimination persisted in the "institutionalization" of people with disabilities and that "segregation" of disabled people "continues to be a serious and pervasive social problem." *Id.* at 12101(a)(2) and (3)(emphases added). Congress did not intend for segregation and institutionalization to be the status quo; the ADA was intended to correct the legacy of discrimination. The

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<sup>5</sup> United States Commission on Civil Rights, Accommodating the Spectrum of Individual Abilities 33 and 34 (1983)(emphasis added)(quoting Bowe, Handicapping America).

Congressional national mandate would eliminate this discrimination against people with disabilities.

Petitioners want to reverse what Congress mandated and to go back to an "equal but separate" standard, where disabled people are forced to accept services in unnecessarily segregated and institutionalized settings. Petitioners urge this standard even when they recognize that the community is an appropriate setting for services. Brief of Petitioners at Question Presented and passim.

Despite Petitioners' repeated assertions, this case is not about the bogus "deinstitutionalization" codeword.<sup>6</sup> Brief of Petitioners at 38. Congress neither required, nor suggested, that the ADA mandates "deinstitutionalization."<sup>7</sup> Nor does the ADA require closure of any institution.<sup>8</sup> Nor does this case present the issue of what services are

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<sup>6</sup> The Helen L. decision has not resulted, despite Petitioners' fears, in "massive deinstitutionalization." In fact since the decision, the nursing home population has increased by more than 4,400 individuals. Pennsylvania Department of Public Welfare, Office of Budget (1998).

<sup>7</sup> This case is not about per se institutionalization or segregation, but about whether Congress recognized unnecessary segregation and unnecessary institutionalization as one form of discrimination to be ended. Throughout Brief of Petitioners, it is clear that they challenge a ban on segregation and institutionalization even when, for specific people, they are unnecessary.

<sup>8</sup> Rather, the ADA mandates that each person with a disability be evaluated individually, rather than a "one-size-fits all," as

necessary. The ADA does not mandate the provision of any services whatsoever.<sup>9</sup> However, once a public entity decides to offer the service, then, and only then, must the service be offered, if appropriate to the individual, in an integrated setting, and if the provision of the service does not present an undue hardship or fundamental alteration.

What this case is about is ending unnecessary segregation and institutionalization; it is about finally achieving integration for disabled people. It is about a real choice to live in the community.<sup>10</sup> If a particular disabled person meets the eligibility criteria for services in an

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Petitioners suggest. Brief of Petitioners at 2.

<sup>9</sup> There is no question that a state's long-term health care services, whether provided in an institution or in the community and whether funded by Title XIX of the Social Security Act or with a state's own funds, are all part of states' seamless "services, programs and activities." See Pennsylvania Department of Corrections v. Yeskey, 118 S.Ct.1952 (1998). The mix of long-term health care services is clearly left to each state. The ADA requires only that the services and programs are provided in a "setting" that is "most integrated," when appropriate, after an individual's needs are reviewed.

<sup>10</sup> Petitioners want to usurp the decision-making of people with severe physical disabilities regarding their integration into society and want to compel them to accept services in unnecessarily isolated and separate settings.

Your amici recognize that there are some persons with disabilities who may believe that an institutional setting is appropriate to meet their needs. We are not arguing the ADA intended that whenever "the most integrated setting" is appropriate, that the person must accept integrated services, but only that services in integrated settings must, at least, be offered. We believe that at a minimum, Congress and the ADA require that a choice be offered - including integrated residential settings.

integrated setting and if a public entity could offer those services in a community setting without a "fundamental alteration," then a public entity that refuses to provide those services an integrated setting, but will provides them only in a segregated setting, would violate the ADA. Thus, this case is about a very fundamental American principle - whether disabled people, like other minorities, will continue to be unnecessarily segregated or will be integrated into their communities and society.<sup>11</sup>

## ARGUMENT

### I. Introduction

People with severe physical disabilities have been forced to live in institutional facilities not because they needed segregated settings, nor because such settings were appropriate -- since physical, mental and developmental disabilities are not contagious diseases, and since Petitioners acknowledge that the services and programs are and can be provided in the community.<sup>12</sup> Rather, public entities have segregated

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<sup>11</sup> Petitioners would not urge "equal but separate" services for blacks, women, or any other minority. The ADA and Congress intended to end the "second class" status of disabled persons. Nevertheless, Petitioners want to usurp the decision-making of people with severe physical disabilities regarding their integration into society.

<sup>12</sup>

Brief of Petitioners, passim.



people in institutions instead of providing them with integrated services in the community, because *historically* that was the way people with disabilities were kept out of sight and away from the public. Such segregation is both unnecessary and is also more costly.<sup>13</sup>

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<sup>13</sup> In 1981, Congress amended the Medical Assistance statute, Title XIX of the Social Security Act, 42 U.S.C. § 1396n, to provide for "Home and Community-Based Services," a medical assistance "waiver" program giving states a cost-effective, administratively non-burdensome process for moving persons from institutional to community settings. *Id.*, at 1396n(c)(2)(A), (D), (4)(A). Petitioners grossly misunderstand how this community waiver provision can be used to give disabled persons a choice to receive services in the community. Brief of Petitioners at 31-32. It is true that the Home and Community-Based waiver does not require an eligible individual receive services in the community "if the [person] preferred institutional care." *Id.* Title XIX is a federal reimbursement statute that reimburses states for their long-term care program for people with disabilities whether in institutions or the community. When states provide services in the community, the federal government via the "waiver" will reimburse the same percentage of federal funds for both community and institutional long-term care services, whether in a nursing home or in the community. Thus, there is no financial disincentive to the state in complying with "the most integrated setting" requirement.

The National Governors' Association recognized early on that "the waiver authority [would] give states greater flexibility to community-based delivery systems where they would serve as a more cost-effective alternative to nursing homes for those in need of long term care." National Governors' Association, Center for Policy Research, An Analysis of Responses to Medical Home and Community-Based Long-Term Care Waiver Program vii (1983).

Moreover, as a result of states opting to use Home and Community-Based waivers, there is no question that those states "have realized significant savings by offering services that allow people with disabilities to live in the community rather than in nursing homes or other institutions." National Conference of State Legislatures, Personal Assistance Services for People with Disabilities, 24 State Legislative Report at 2 (Jan. 1999)(emphases added).

Petitioners do not tell this Court that, in enacting the ADA, Congress recognized that the Rehabilitation Act had not fulfilled the "compelling need ... for the integration of persons with disabilities into the economic and social mainstream of American life,"<sup>14</sup> nor do Petitioners mention that the ADA was enacted to "break down barriers to the integrated participation of people with disabilities in all aspects of community life."<sup>15</sup> Rather, they pretend that the ADA did not recognize the shortcomings of the Rehabilitation Act.

Fourteen years ago, this Court stated, in addressing the Rehabilitation Act of 1973, 29 U.S.C. § 794, that discrimination against people with disabilities was "most often the product, not of invidious animus, but rather of thoughtlessness and indifference - of benign neglect." Alexander v. Choate, 105 S.Ct 712, 717 (1985).

Since the 1990 enactment of the ADA, the continued *unnecessary* segregation of people with disabilities in institutional nursing facilities can no longer be the result of "benign neglect."<sup>16</sup>

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<sup>14</sup> S. Rep. No. 116, 101st Cong. at 20 (1989)(emphasis added).

<sup>15</sup> H.R. Rep. No. 485 (III) at 49-50 (1990)(emphasis added), reprinted in 1990 U.S.C.C.A.N. at 472-73.

<sup>16</sup> Neither of the two respondents, LC and EW, require institutionalization. L.C. v. Olmstead, 138 F. 3d 893, 895, n.2 (11th Cir.

When public entities refuse to reallocate the same funds from overwhelmingly segregated settings to integrated settings, when public entities could in fact save funds by providing integrated services,<sup>17</sup> and when a public entity continues to allocate funds primarily in segregated facilities, that is *unnecessary* segregation and is not benign. The refusal to reallocate existing funds causes segregation and is deliberate. As Congress found, such discriminatory practices continue through "outright intentional exclusion" and "segregation." 42 U.S.C. § 12101(a)(5).

The ADA was supposed to be the clarion call to end unnecessary segregation. No longer would segregation be permissible when Americans with disabilities could, and would choose, to live

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1998). Neither did Idell Smith. Helen L., *supra*, 46 F.3d at 329, n.6. Thus, these three women were unnecessarily segregated and institutionalized.

<sup>17</sup> Amici emphasize that this case is not about increasing expenditures. To the contrary, states will save funds. See *infra*, n. 52. Unlike the reallocation of existing funds to community-based programs, there are other provisions of the ADA which, in fact, may require public entities to expend new funds to eliminate discrimination. See e.g., public entities must construct curb cuts when they resurface streets, 28 C.F.R. § 35.151(e), Kinney v. Yerusalum, 812 F. Supp. 548 (E.D. Pa. 1993), *aff'd*, 9 F.3d 1067 (3d Cir. 1993), *cert. denied*, 114 S.Ct. 1545 (1994); make new buses and subways accessible, 42 U.S.C. § 12142; and develop a paratransit system, 42 U.S.C. § 12143.

integrated in the community. Nevertheless, such segregation still persists and is the subject of the instant case.

Senator Lowell Weicker, an original sponsor of the ADA, told Congress the impact the ADA would have on segregation in institutional settings:

For years, this country has maintained a public policy of protectionism toward people with disabilities. We have created monoliths of isolated care in institutions.... It is that isolation and segregation that has become the basis of discrimination faced by many disabled people today. Separate is not equal. It was not for blacks; it is not for the disabled.<sup>18</sup>

## II. Integration, Ending Segregation and Choice Are the ADA's Fundamental Principles

The ADA is the anti-discrimination, civil rights statute for persons with disabilities. Congress, the Administration and people with disabilities understood, when the ADA was passed, that segregation

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<sup>18</sup> Hearing Before the Senate Committee on Labor and Human Resources and the Sub-Committee on the Handicapped, 101<sup>st</sup> Congress, 1<sup>st</sup> Session, 215 (1989)(emphases added). See also, Sen. Harkin "[f]or too long, individuals with disabilities have been excluded, segregated, and otherwise denied equal, effective and meaningful opportunity to participate in the economic and social mainstream of American life. It is time we eliminate these injustices." 135 Cong. Rec. S19801 (1989)(emphasis added). Rep. Miller, "It has been our unwillingness to see all people with disabilities that has been the greatest barrier to full and meaningful equality. Society has made them invisible by shutting them away in segregated facilities." 136 Cong. Rec. H2447(1990)(emphasis added).

and particularly unnecessary segregation of persons with disabilities would end. Now, less than ten years since its enactment, Petitioners want to eliminate one of the most fundamental aspects of the ADA -- integrating disabled persons, ending unnecessary isolation and discrimination, and giving people with disabilities a choice of settings where they will receive services. They can do so only by repeatedly mischaracterizing Congress' knowledge and intentions.

There is no doubt whatsoever that both houses of Congress intended that ending unnecessary segregation was integral to the ADA.

The definitive Committee in the House wrote:

The purpose of Title II is to continue to break down barriers to the integrated participation of persons with disabilities in all aspects of community life....While the integration of persons with disabilities will sometimes involve substantial short-term burdens, both financial and administrative, the long-range effects of integration will benefit society as a whole....<sup>19</sup>

The definitive Committee in the Senate wrote:

The Americans with Disabilities Act (ADA) will permit the United States to take a long-delayed but very necessary step to welcome individuals with

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<sup>19</sup> House Judiciary Committee. House of Representatives, Committee on the Judiciary Report No. 101-485 Part 3, pp.49-50 (101<sup>st</sup> Congress, 2d Sess.), May 15, 1990. (Emphases added).

disabilities fully into the mainstream of American society.<sup>20</sup>

At time of signing of ADA, President George Bush stated:

[t]his historic Act is the world's first comprehensive declaration of equality for people with disabilities....

This Act is powerful in its simplicity. It will ensure that people with disabilities are given the basic guarantees for which they have worked so long and so hard. Independence, freedom of choice, control of their lives, the opportunity to blend fully and equally into the right mosaic of the American mainstream.

And now I sign legislation which takes a sledgehammer to another wall, one which has for too many generations separated Americans with disabilities from the freedom they could glimpse, but not grasp.... Let the shameful wall of exclusion finally come tumbling down.<sup>21</sup>

At the same signing, Attorney General Dick Thornburgh stated that

"[t]his historical civil rights legislation seeks to end the unjustified

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<sup>20</sup> S. Rep. No. 116, 101st Cong., 1st Sess. 6 (1989)(reprinted in 1990 U.S.C.C.A.N. 267, 268; see H.R. Rep. No. 485 (I), 101st Cong., 2d Sess.24 (1990).

<sup>21</sup> Reprinted in National Council on Disability, Equality of Opportunity: The Making of the Americans with Disabilities Act at App. G (1997)(emphases added).



segregation and exclusion of persons with disabilities from the mainstream of American life...." *Id.*, at 3 (Emphasis added).<sup>22</sup>

Both by statute, 42 U.S.C. § 12182(b)(1)(B)(applicable to Title III private entities) and by federal regulation, 28 C.F.R. § 35.130(d)(applicable to Title II governmental entities), Congress and the ADA define as "discrimination" "services, programs, and activities" that a public entity does not offer "in the most integrated setting appropriate to the needs of qualified individuals with disabilities"(emphasis added). Petitioners challenge this integration requirement.<sup>23</sup> This regulation (and statute) ensures that people "interact with non-disabled persons to the fullest extent possible." 28

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<sup>22</sup> Attorney General Thornburgh had testified that "many persons with disabilities in this Nation still lead their lives in an intolerable state of isolation and dependence." S. Rep. No. 116, 101st Cong., 1st Sess. 7 (1989); H.R. Rep. No. 485 (II) at 32 (1990), reprinted in 1990 U.S.C.C.A.N. at 313.

<sup>23</sup> Petitioners constantly use "least restrictive treatment," a term used in the Developmental Disabilities Assistance and Bill of Rights Act 42 U.S.C. §§ 6000 et seq., even though neither the ADA's statute nor regulations ever use it. Brief of Petitioners, passim. Where Congress clearly intended the ADA to be a civil rights, antidiscrimination statute, the Developmental Disabilities Assistance and Bill of Rights Act was a funding statute that imposed no comparable antidiscrimination prohibitions. The ADA imposes no affirmative obligations on public entities to provide any services, but only prohibits discrimination once a public entity does provide services.

C.F.R. § Part 35, App. A. § 35.130(d). Often times, this can be achieved, where appropriate for an individual, only in the community.<sup>24</sup>

Petitioners would eliminate the Congressional goal of ending discrimination against people with disabilities in society's segregated settings, including nursing facilities.<sup>25</sup> They can do this only by belittling and ignoring the strong record which shows Congress was well aware of the unnecessary segregation and institutionalization of severely physically disabled persons in such settings and intended to end it.<sup>26</sup> Rather than complying with the ADA and offering services and programs in integrated settings, Petitioners attempt to seek to have this Court eviscerate the ADA, eliminating what Congress wanted explicitly to achieve.

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<sup>24</sup> Instead of complying, Petitioners want to be able to continue unnecessarily segregating and unnecessarily institutionalizing people with disabilities who neither require nor want to be segregated.

<sup>25</sup> There is no question that nursing facilities are segregated. "Because she is required to receive services in a nursing home, Idell S. has no contacts with non-disabled persons other than the staff of the nursing home and visits from her two children." *Helen L. v. DiDario*, 46 F.3d 325, 329 (3d Cir. 1995)(emphasis added).

<sup>26</sup> See infra, at nn. 32-38.

The needs of the person with a physical disability are usually quite objective, for example, needing assistance getting in and out of bed, assistance washing, taking medicine, eating. If there is only one setting where those needs can be met, then by definition it is the "most integrated." The issue of "most integrated" arises only when there are several settings where a person's needs could be appropriately met. When there are various settings, Congress intended that public entities had to make "the most integrated setting" available. Whether or not the person chooses "the most integrated setting" is up to the person with the disability, since there are persons who may believe that institutional programs are more appropriate to their needs. Petitioners want to perpetuate the unnecessary segregation, rather than offer eligible disabled persons the choice of integrated living.

### **III. Congress Knew That Americans with Disabilities Have Been Discriminated Against and Kept Unnecessarily "Out of Sight" In Residential Nursing Facilities and Other Isolated Institutions**

Seventeen years after the enactment of Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, Congress found that people with disabilities still were "subjected to a history of purposeful unequal treatment...." 42 U.S.C. § 12101(a)(7). Congress certainly

knew that isolation, segregation, and institutionalization still existed in 1990. But Congress went even further, finding that

the continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities to compete on an equal basis and to pursue those opportunities from which our free society is justifiably famous, and costs the United States billions of dollars in unnecessary expenses resulting from dependency and nonproductivity. 42 U.S.C. 12101(a)(9)(emphases added).

Congress knew that people with severe physical disabilities were both injured in institutions <sup>27</sup> and were unnecessarily segregated in nursing facilities. <sup>28</sup> Before the enactment of the ADA, Congress

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<sup>27</sup> See Martha Minow, Making All the Difference: Inclusion, Exclusion and American Law 175 (1990)("[T]he institution itself created circumstances of powerlessness and dehumanization.... The sheer fact of institutionalization stigmatized the person and, in many institutions, defined the individual as less than a person"); Susan Stefan, A Moment of Listening: Discrimination Against People with Psychiatric Disabilities and the Americans with Disabilities Act (1999)(Forthcoming)("Institutional living is defined not by size, but by the measure of control an individual retains over his or her own life and the most basic decisions about how to live it: when to go to sleep and get up in the morning, when and what to eat, the decorations of one's home and the choice of one's companions").

<sup>28</sup> Approximately 10.9% of the residents in nursing homes are under 65 years old. National Center for Health Statistics, Centers for Disease Control and Prevention (CDC), U.S. Department of Health and Human Services, An Overview of Nursing Homes and Their Current Residents: Data from the 1995 National Nursing Home Survey, Table 6 at 6 (January 23, 1997). In 1990, 4,231 people under the age of 25 were in nursing homes, Census Bureau Reports, Nursing Home Population: 1990 (CPH-L-137), and 57,017 people between the ages of 25 and under 50. Bureau of the Census, 1990 Census Population (STP 16).

held public forums throughout the country.<sup>29</sup> Many witnesses spoke of the segregation and injurious effects of nursing homes (and other institutional settings), referring "to the isolation, dependence and depression bred in nursing homes, as well as their enormous cost."<sup>30</sup>

Congress heard testimonies from people who had previously been institutionalized in nursing facilities and were now successfully living in the community. For example, Laura Cooper, a 32 year old practicing lawyer with multiple sclerosis who uses a motorized wheelchair for ambulation, testified about the severe isolation she experienced living in a nursing home because the state in which she lived did not have community programs.<sup>31</sup> Dr. William Spencer testified that "the absence of [community] services and support for independent living can make it nearly impossible to attain an autonomous lifestyle with control of one's own life. The alternative

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<sup>29</sup> Clearly hearing how disabled persons were treated prior to the ADA's enactment, Congress had a record from which to find that "historically society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem." 42 U.S.C. § 12101(a)(2).

<sup>30</sup> Stefan, supra n.27.

<sup>31</sup> Hearings before H.R. SUBCOMMITTEE On Civil and Constitutional Rights, Committee on the Judiciary (10/11/89), reprinted in Arnold & Porter ADA Comm. Print. 1990 (28C) at \*1975-77. Ms. Cooper lives in her own apartment.

becomes chronic care in the hospital for the severely disabled or custodial placement in a nursing home."<sup>32</sup>

Ms. Janna Shishler testified that

on a crisp fall evening 10 years ago I became one of the continually expanding number of Americans with disabilities. My admission to the group took only a matter of seconds but the result has altered my life dramatically.... Since that night I have been a quadriplegic with no muscular function below my biceps. I was a 19 year old sophomore at Indiana University....

I believe that I am not an exception to the rule. The majority of persons with disabilities do not relish the thought of sitting day after day in a bedroom or nursing home. ... The [ADA] will allow many of the disabled who have heretofore been ostracized from society to become contributing members.<sup>33</sup>

One person testified about her 23 year old friend, Joe, who has lived in a nursing home since he had an accident at age 17. He was

placed in a nursing home one hour away from his friends and family.... [H]is self-esteem is not great. The battery for his motorized wheelchair is missing. No one will take responsibility for losing it....[H]e is unable to have his own telephone. He cannot have cable TV, either. He is again rooming with a man

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<sup>32</sup> Hearings before H.R. Subcommittee. on Select Education, Committee on Education and Labor. (8/28/89) reprinted in Arnold & Porter Comm. Print. 1990 (28A) at \*1514.

<sup>33</sup> Hearings before H.R. SUBCOMMITTEE. on Select Education, Committee on Education and Labor (10/6/89) reprinted in Arnold & Porter ADA Comm. Print. 1990 (28A) at \*1741.



who is in his nineties and is dying.... Joe was ready to get the wheels turning again so that he can moved on. Passage of the ADA will play a key role in his success.<sup>34</sup>

Mary Ella Linden, a 58 year old woman, testified about living in a nursing home for 23 years, where her parents had placed her because they considered her "too crippled to compete."

You see before you a woman who did not learn until August 10, 1987 that she had the strength to help with anything or to change her own outlook. My father had always chosen my path until his death in 1964. There was no alternative housing situation for my father to use for me after his death, but a nursing home. And so, at the age of 34, I was placed in a retirement home with my mother upon his death. And upon her death I was placed in the adjacent nursing home.... God only knows how many contributions society has missed because there were no provisions for the disabled to move about freely and determine their own lives. I pray that the ADA will be passed as soon as possible so that we may become another 'melted minority'.<sup>35</sup>

Eleanor Smith testified that

I reside in a nursing home right now. I am an active-minded person though physically disabled. I would have preferred to be able to live outside the nursing

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<sup>34</sup> Statement of Marcie Roth. Joint hearings before the U.S. Senate Subcommittee on the Handicapped of the Committee on Labor and Human Resources and H.R. SUBCOMMITTEE on the Select Education of the Committee on Education and Labor (9/27/88) reprinted in, Arnold & Porter ADA Comm. Print. 1990 (28B) at \*1110-11, 1113-14.

<sup>35</sup> Id., at \*988-89.

home in order that I might have independence to arrange my living style to meet many basic rights not currently available through a nursing home residence. These basic needs and rights include as follows: the right to maintain the privacy of telephone calls and mail and correspondence. The right to have some input into my general care and therapy. The right for a quiet surrounding ...that would enable me to do the personal tasks I would wish to do.<sup>36</sup>

Justin Dart told Congress that

[i]t is the status quo discrimination and segregation that are unaffordable, that are preventing persons with disabilities from becoming self-reliant and that are driving us inevitably toward the economic and moral disasters of giant, paternalistic welfare bureaucracies ... in unjust, unwanted dependency.... We appeal to you not for more welfare, not for more segregation in nursing homes....<sup>37</sup>

Despite the Congressional statutory Findings and Purposes, there are many people with physical disabilities for whom the ADA's anti-discrimination and "most integrated setting" are critical if they are to live in the community. For example, Idell Smith, 43, was paralyzed from the waist down due to meningitis. She used a wheelchair for

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<sup>36</sup> Id., at \*1161(emphasis added).

<sup>37</sup> Hearings before Joint Hearings before the U.S. Senate Subcommittee on the Handicapped of the Committee on Labor and Human Resources and H.R. SUBCOMMITTEE on the Select Education of the Committee on Education and Labor (7/18/89) reprinted in, Arnold & Porter ADA Comm. Print. 1990 (28B) at \*1326(emphasis added).

ambulation and needed assistance in getting in and out of bed. Helen L., supra at 328. She wanted to live at home with her two children instead of being unnecessarily segregated in a nursing facility. The state agreed that "although Idell S. is not capable of fully independent living, she is not so incapacitated that she needs the custodial care of a nursing home." Id. at 328. It was stipulated that "[t]he setting for the provision of attendant care services appropriate to the needs of Idell S. is in the community" and "[w]ith attendant care services in the community, nursing home care would not be appropriate for Idell S." Id., at 329, n.6. Nevertheless, and despite the enactment of the ADA, Pennsylvania refused to save \$10,000 per year by providing Idell Smith the same or similar services in the community that they paid for her in a nursing home. Id. at 329. Ms. Smith's situation parallels that of Respondents here when it is premised that the necessary services could be provided in either a residential or institutional setting.

Larry McAfee, a thirty-four year old man with quadriplegia as a result of an accident, was transferred from one institution to another "like a sack of potatoes" over a period of four years.<sup>38</sup> Georgia would not pay for community services but would pay only the costs of nursing

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<sup>38</sup> Peter Applebome, An Angry Man Fights to Die, Then Tests Life, N.Y. Times, Feb. 7, 1990, at A 1.

home care, where he lived for months, even though he was not ill, nor did he require any institutional care.<sup>39</sup> In the nursing home, he was told when to eat, sleep, and even what he could watch on his own video recorder.<sup>40</sup> Until he obtained the same services in the community that he had received in the segregated nursing home, he had requested the "right to die."

Jeff Gunderson has cerebral palsy. From age eighteen until he turned twenty-seven, he lived in a nursing home.<sup>41</sup> He wound up in a nursing home after his parents divorced and his mother could not lift him out of bed or care for him. "Gunderson's mother had little choice: she put her teenage son in a nursing home."<sup>42</sup> He was required to follow the same regimen as everyone else. He went to bed at 7 P.M., when his eighty year old roommate went to bed. His food was bland; he was tied to his bed; he was dragged into cold showers as punishment; he had to use the bathroom on a schedule convenient for the nurses or

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<sup>39</sup> Steven A. Holmes, Disabled People Say Home Care is Needed to Use New Rights, N.Y. Times, Oct. 14, 1990, at Sec. 1, 2.

<sup>40</sup> Joseph Shapiro, Larry McAfee, Invisible Man: The Agonizing Fight to Prevent Legalized 'Suicide', U.S. News & World rep., Feb. 19, 1990, at 59.

<sup>41</sup> Joseph Shapiro, No Pity 237 (1993).

<sup>42</sup> Id., at 238.

they would put ice cubes down his pants.... On several occasions, Gunderson says he was given a suppository before sleep and, since he could not move by himself, he would spend the night lying in his own feces.... [D]ays were spent watching soap operas. 'Many times I wanted to kill myself,' he says. 'I planned it, too'.<sup>43</sup>

Mr. Gunderson now lives in a subsidized apartment and has an attendant who helps him dress, bathe, use the toilet, and eat -- the same daily activities performed in the nursing home. He also works, bowls, eats out, stays up late watching movies.

'I can go out and do things for myself.... I used to be a shy person because of all those years living in a nursing home'... 'I always said if I had to go back, I'd rather be six feet under'.<sup>44</sup>

Other people with severe physical disabilities have faced similar unnecessary segregation. An award winning magazine, which focuses exclusively on disability issues, devoted one issue to testimonies from disabled people who had lived in nursing homes.<sup>45</sup>

- ◆ People don't know there are kids in nursing homes. I was in a nursing home for thirteen years. I had to fight to get out. It was the beginning of my life at age 22. Claude H., Connecticut.

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<sup>43</sup> Id. See also, Timothy Diamond, Making Gray Gold: Narratives of Nursing Home Care (1992).

<sup>44</sup> Id. at 240

<sup>45</sup> You Choose, 6 The Mouth (Nov. 1995).

- ◆ Being in a nursing home, I was amazed at the number of people who were forced there because they had no services at home. Everything should be done to keep families together and keep people at home, not in nursing homes. Pat A., Michigan.
- ◆ I love being in a real home again. All my friends are welcome. I made my own curtains, do my own shopping, and I work as a volunteer. Dolores S., Missouri.
- ◆ Every day of every year, I wanted to go home. Norm B., Montana.
- ◆ For what Medicaid paid to that nursing home, I could have lived like a king. But it was like being a guest in a stranger's house. And the stranger doesn't want you there. Arthur A., Maine.
- ◆ I was put in a nursing home because my family didn't think I could manage on my own.... One staff guy beat up patients. I saw it.... Beverly H., Pennsylvania.
- ◆ I was existing. It got to the point there was no use. I was just going to die. I almost gave up. Jeanne L., New Mexico.
- ◆ I was forced to stay there. I had no other choice. You keep asking yourself, 'Is this America?' Jim B., Michigan.

These people represent many persons with physical disabilities who were and are unnecessarily and improperly segregated in nursing homes.<sup>46</sup> Each one of them did not have a choice -- each needed

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<sup>46</sup> Approximately 70 percent of persons 65 years and younger segregated in nursing homes are in nursing "homes" with 100 beds or more. Public reimbursements support 97 percent of all residents in nursing homes. National Center for Health Statistics, Centers for Disease Control and Prevention (CDC), U.S. Department of Health and Human Services, An Overview of Nursing Homes and Their Current Residents: Data from the 1995 National Nursing Home Survey, Table 6,



assistance getting in and out of bed, assistance eating, bathing, and toileting, which could easily be provided in an integrated setting. Without services, they could not survive.<sup>47</sup> Each wanted to live in the community. Each was receiving state funded services and the only issue was the setting - whether integrated in the community or segregated in an institution.

But for the ADA, these people would not be integrated. Petitioners would leave these people with no right to live in the community, "the most integrated setting appropriate for [their] needs" and would undo what Congress intended.

**IV. Disabled Persons Want An Opportunity and Real Choice to Reside In the Community And Not Be Unnecessarily Segregated**

People with physical disabilities do not want to be forced to accept segregated services and programs. At the minimum, they want the real choice of where they will receive these services. This is particularly applicable to persons with severe physical disabilities who, in order literally to survive, require assistance, whether it be in the form

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at 6 (January 23, 1997).

<sup>47</sup> Amici fully recognize that without these services, such as assistance getting in and out of bed, food preparation, toileting assistance, many people with severe disabilities would die.

of personal attendant services, such as assistance in getting out of bed, preparing food, assistance with toileting, or home health care. Without these services, many people with severe physical disabilities will end up hospitalized or worse.

One national survey of people with disabilities and their families found that

There is an overwhelming preference ... to remain in their own homes for as long as possible. The majority of people with disabilities do not live in institutions and are able to remain in their homes and communities. Most community-based long-term care is provided by family members and friends.<sup>48</sup>

When disabled persons and their families were asked where they wanted help with everyday activities, the results were quite stark: 47% strongly dislike having care provided in a nursing home or other residential settings; 48% strongly wanted assistance in the person's own home.<sup>49</sup>

Despite the "overwhelming preference" of Americans, "the majority of public spending ... remains devoted to institutional forms

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<sup>48</sup> Enid Kassner and Robert W. Bectel, Midlife and Older Americans with Disabilities: Who Gets Help? A Chartbook 21 (1998).

<sup>49</sup> Id. at 66.

of care,"<sup>50</sup> even though community-based services are generally less costly than residential nursing facilities and public entities would actually save funds. In a national comparison of institutional care versus home and community base care, the National Conference of State Legislatures found that:

the annual cost of institutional care for people with disabilities is more than double the average annual cost of providing home-and community-based services. In 1996, institutional care cost an average of \$94,348 per person, compared with \$14,902 per person for community-based services, with wide variation, depending on whether services include residential care. States across the country have realized significant savings by offering services that allow people with disabilities to live in the community rather than in nursing homes or other institutions.<sup>51</sup>

Petitioners want the right to tell people with disabilities that they must remain segregated and that the States should have the right to decide the setting where the disabled person will receive essential

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<sup>50</sup> Id. at 65. The fact that it is less expensive to provide services in the community compels the inference that it is a wilful lack of desire to rectify the situation.

<sup>51</sup> National Conference of State Legislatures, State Legislative Report- Personal Assistance Services for People with Disabilities, 24 State Legislative Report at 2 (Jan. 1999).

services.<sup>52</sup> States would never tell blacks or women where they must live or that they must receive services in segregated "blacks only" or "women only" settings. Assuming arguendo there are two "appropriate" settings, one integrated into the community and one segregated unnecessarily in an institution, States should never require a segregated setting; public entities should never be permitted to forcibly segregate when such segregation is not necessary.

By definition, if there are two appropriate settings, there are no justifiable reasons to compel segregation. If people with disabilities have no choice between receiving services in a segregated or integrated setting, then being forced to be institutionalized is a non-choice. Real choice requires that funds be comparably available for both settings, so the individual can decide where she or he wishes to receive the services without regard to the historical distribution of funds. States were not permitted to choose segregation for blacks as appropriate, nor are they permitted to choose segregation for disabled persons.

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<sup>52</sup> Brief of Petitioners at Question Presented and passim. Petitioners want the right to decide the setting in which the person with a disability will receive services even if the setting is unnecessarily segregated and unnecessary whatsoever.

### Conclusion

People with severe physical disabilities, like all Americans, want to control and direct their own lives, make decisions for themselves, be allowed to take risks and even fail, have opportunities to participate in all aspects of community life, and take responsibility for their actions, including responsibilities as part of their community.

For too long, disabled persons have been shut away, out of sight. How this Court decides the instant case and the ADA's "integration" requirement will decide whether or not many people with disabilities will have the choice to live in the community or be unnecessarily segregated.

Respectfully submitted,

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